

**Submission from**

**Victorian Young People In Nursing Homes Consortium**

**to**

**Productivity Commission Inquiry into Disability Care and Support**

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***To:***

The Productivity Commission  
Level 2, 15 Moore Street  
Canberra City ACT 2600, Australia  
disability-support@pc.gov.au

***From:***

Victorian Young People In Nursing Homes Consortium  
c/- PO Box 900  
Northcote  
Victoria 3070  
policy@vcasp.org.au

Contact person:    Marc Paradin

## **Executive Summary**

The Victorian Young People In Nursing Homes (YPINH) Consortium note the valuable contributions made to the development of a National Disability Insurance Scheme (NDIS) by the Productivity Commission, and welcomes the opportunity to contribute to the inquiry into the issue of Disability Care and Support.

The Consortium believes that identified priorities for the Commission to consider in relation to the issue of younger people in nursing homes are:

- to provide of a range of viable and innovative options for people with disabilities – in areas of accommodation, rehabilitation and support
- to provide timely and accurate evaluation and ongoing individual reviews of disability
- to provide a range of core and individual funding options
- to increase resources for prevention of acquired disability, and for early intervention
- to guarantee access to funding and support regardless of disability and level of fault
- to include degenerative conditions such as Multiple Sclerosis within a NDIS
- to increase the knowledge and skill base of workforce, with accompanying fair payment of workforce
- to recognise that the housing of people with disabilities in the age group 50-65 is currently an 'at need' area

The Consortium recognises the positive contribution that an appropriately resourced NDIS Scheme can make for those younger people and their families currently in Residential Aged Care, and the many young people at risk of future entry into Aged Care facilities.

## **Introduction – About the Consortium**

The Victorian YPINH Consortium, which began in September 2001, comprises representatives from groups such as MS Society, Melbourne City Mission, Victorian Coalition of ABI Service Providers, Office of the Public Advocate, and representation and participation by young people in nursing homes, their families and advocates.

The Consortium provides an opportunity for young people in nursing homes and disability sector workers to meet and determine issues and potential options in order to improve the lives of people residing in, or in consideration for entry to nursing homes/aged care facilities.

The Consortium has advocated at a State and Federal level (including a National Summit about the issue of YPINH, in 2002), for recognition of the issue of YPINH, and the development of policies and initiatives such as *my future my choice*, developed by the Victorian State Government through the Federal COAG initiative.

## **About YPINH – Definitions / prevalence**

The Victorian YPINH Consortium recognises a “Young Person In a Nursing Home” (YPINH) or “Young Person In Residential Aged Care” (YPIRAC), to be defined as a person of under 65 years of age, who is placed on either a full or part-time basis within a residential aged care facility, or similar facility.

Many YPIRAC may have more than one significant disability, however the primary disability groups of YPIRAC can be defined as Acquired Brain Injury (ABI), Neurological, and Physical.

Nationally, as at June 2008, there were 6,752 residents under the age of 65 years in residential aged care, comprising 4.2% of all residents. Permanent younger residents totalled 4,540, with 3,939 being between the age of 50-65, and 601 being under the age of 50. Of the 8 available categories for level of need, 72% of younger people in permanent RAC were classified within the three highest categories. (AIHW 2009, Table 4.2, Table 4.29a )

A 2005 Senate report has noted significant recent increases in the numbers of young people with disabilities who are accommodated in aged care facilities (Senate Community Affairs References Committee, 2005)

### **Significant current issues – areas of need / issues faced by YPINH**

Whilst progress has been made in reducing numbers of people within RAC, a large percentage of YPIRAC remain within the aged care system, and large numbers remain at risk of entry or re-entry into RAC, principally as a result of low levels of support funding and resources relative to identified need.

As the mid-term Victorian Government review into *my future my choice* and YPIRAC states:

*“There is significant unmet need of YPIRAC ..... While the Program will make a positive contribution to this previously neglected group, many YPIRAC will continue to have significant needs that cannot be met within current funding allocations.”* (Ryan, Lopata, Yeomans, 2009. p.8)

Where alternatives to RAC have been found, there currently remains a concern that such alternatives may not be adequately resourced to meet the needs of residents.

These concerns include areas such as:

- Ensuring adequate training levels and skill levels of care and rehabilitation staff
- Ensuring 24 hour care is available for residents
- Provision of individualised rehabilitation programs, equipment, and facilities
- Adequate connection with family, friends and the community

The Consortium recognises that the current levels of allocation leave a number of communities and groups of individuals at a disadvantage with regard to access of appropriate services, and levels of support.

Specifically, the Consortium recognises the following areas of additional need:

- Individuals in nursing homes, or at risk of entry to nursing homes, aged 50-65.
- People with high medical/behavioural/cognitive needs and changing needs
- People in regional, rural and remote areas
- Culturally and Linguistically Diverse communities and Indigenous people

## **About the proposed NDIS – advantages of the scheme and potential issues requiring response**

### Strategies for prevention of entry into system

Preventing acquired disabilities from occurring - TAC-styled public campaigns and community consciousness-raising, particularly around the risks of ABI's and preventable injuries, which as a result was able to result in a partial reduction of numbers of such people entering the health system, is an important component in addressing the issue of YPINH.

Early information - Consciousness-raising campaigns may provide additional information on accommodation options and resource options to individuals and their families in circumstances where an ABI or other disability-related condition occurs.

### Who's in and who's out?

If the NDIS Scheme is not planning to include disability related to 'general ageing', this raises the potential for a divide between YPINH who qualify for NDIS, and those who do not. Where many people in RAC are in the 50-65 age bracket, and where this has been identified as a significant 'at need' group, it is important to define if such individuals will be appropriately covered under a future policy. The YPINH Consortium holds the view that the majority of conditions, which result in the inclusion of individuals under the age of 65 to nursing homes, should not be considered as 'general ageing' conditions. To this end, it is important to develop an appropriate evaluation tool, which identifies, in a timely manner, all conditions affecting an individual.

### Self management

The Consortium strongly endorses the rights of young people with a disability to manage their own lives, but recognises that some people cannot make all decisions affecting their lives. Whilst the majority of younger people will be able to self-determine their lives, there is a need for an appropriate framework for delegated decision-making, where such exceptional circumstances are required, to be regularly reviewed to accommodate any potential return of capacity by an individual.

## **Proposed Framework of Action**

The Consortium notes the following two areas of recommended action. These are:

### Increase skill level and knowledge base of workforce

It is envisaged that the provision of an appropriately skilled and trained workforce will be a significant costing, across all areas of disability, for the NDIS.

Specific to the area of YPINH, it is vital that a non-RAC workforce maintains the skills in high-support care that currently exists within the aged care sector, and the capacity to provide that care at up to 24-hour-per-day levels. In addition, there is a requirement to ensure that knowledge and skills in the workforce are specific to the social and physical needs of young people with disabilities, and the particular knowledge required in the management of conditions such as Acquired Brain Injury and Multiple Sclerosis.

### Develop a variety of accommodation options

It is noted that the proposed NDIS locates responsibility for affordable housing with the housing sector not the disability sector.

The Consortium in response notes its concern regarding current broad levels of housing affordability and accessibility, and the potential impact of the development of larger 'housing associations', which have resulted in amalgamations of smaller disability-specific housing agencies.

The Consortium holds the view that accommodation is an integral part of any support scheme, and that at a minimum there should be mechanisms put into place to ensure effective communication and movement between the disability and housing sector, to advocate and cater for a flexible array of accommodation needs, of all people with a disability. To this end, a benchmark is required for standards of accommodation and support, which specifically includes the issue of young people in nursing homes.

## **Conclusion - Anticipated outcomes of NDIS**

As a broad overview, younger people with an ABI, neurological or physical condition, given appropriate care, resources and timely rehabilitation, can and do improve and recover functional abilities. The NDIS, where appropriately resourced and managed, can play a vital role in maximising this inherent potential.

Whilst programs such as *my future my choice* are addressing the issues of YPINH in part, there remains a significant lack of access to appropriate, non-RAC accommodation and services, particularly for people aged 50-65.

Increased access to services, adequate financial support, improved disability workforce skills and improved cross-sectoral communication, are fundamental elements which will result in improvements to the issue of YPIRAC, and which should be fully incorporated within a NDIS. Furthermore, a NDIS should hold the aim of increasing the range of accommodation options currently available for individuals and their families.

The Victorian Young People In Nursing Homes Consortium offers its strong support to the current inquiry into Disability Care and Support, and the future development of a National Disability Insurance Scheme.

## References

Australian Institute of Health and Welfare (2009), *Residential aged care in Australia 2007-08: A Statistical Overview*. AIHW, Canberra.

Ryan, Lopata, Yeomans (2009), *Mid-Term Review, Younger People In Residential Aged Care (YPIRAC) Program*. Urbis. Melbourne.

Senate Community Affairs References Committee (2005), *Community Affairs References Committee: Quality and equity in aged care*. Canberra.

## Further Resources

Victorian Young People In Nursing Homes Consortium – Call to Action, 2010

Winkler, Farnworth, Sloan, Brown (2010) *Getting Out – Mid-term Evaluation of the National Younger People In Residential Aged Care Program*